

Creating a Protocol to Increase Advance Care Planning Conversations
with Heart Failure Patients in an Outpatient Clinic

By

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Abstract

Problem: Heart failure is a chronic, progressive disease with a high symptom burden and mortality rate. Many patients in this population do not understand the disease trajectory, nor do many cardiologists have advance care planning (ACP) conversations with their patients. This combination increases the probability that patients and families will experience aggressive care with unnecessary pain at the end of their lives. ACP conversations can decrease the distress of both families and patients with chronic diseases; however, only 5-15% of physicians have these discussions with their patients. There are various tools available in the literature to assist providers in engaging in ACP conversations, but there is a lack of protocol that addresses comprehensive aspects of ACP conversations at outpatient heart failure clinics.

Project Aim: The aim of this quality improvement project was to chronicle the development and evaluation of an evidenced-based protocol to improve ACP processes in a heart failure clinic. This comprehensive protocol incorporated various tools and resources regarding ACP.

Project Method: This quality improvement project was conducted using a literature search, gathering, analyzing and synthesizing the data and producing a protocol for ACP in an outpatient heart failure clinic. The protocol was reviewed and evaluated by cardiology experts in the field using the modified AGREE II tool.

Results: Two cardiology providers with expertise in heart failure reviewed the protocol and responded with quantitative data from the modified AGREE II tool and qualitative data including implementation feasibility, protocol usefulness, and suggested protocol improvements. There were five domains in the modified AGREE II tool, with a score of > 70% required to be considered high quality. Domain scores ranged from 79%-92%. Both experts stated the protocol

would be useful but did identify barriers including administrative barriers, length of appointment times, and need for additional staff.

Conclusion: A protocol for increasing ACP conversations in an outpatient heart failure clinic is feasible and would be useful to both patients and staff, however known barriers would need to be overcome to facilitate implementation.

Keywords: Advance Care Planning, Heart Failure, Protocol, Advance Directives,
Advance Care Planning Conversations, Outpatient Clinic

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Creating a Protocol to Increase Advance Care Planning Conversations with Heart Failure Patients in an Outpatient Clinic

Heart failure is a chronic condition that occurs when the heart muscle is weakened and fails to pump blood effectively throughout the body, leading to difficulty breathing, fatigue and extremity swelling (Centers for Disease Control and Prevention [CDC], 2016). It is a progressive disease that rivals cancer in terms of symptom burden (Lewin & Shaefer, 2017). It affects almost 5.7 million Americans, costs \$30.7 billion per year, and has a mortality rate of 50% within 5 years of diagnosis (Ba, Gelfman, Horton & Goldstein, 2017; Lewin & Schaefer, 2017). Heart failure is projected to increase 46% by 2030 and will affect greater than 8 million people (Benjamin et al., 2017).

As the symptoms of heart failure progress, so does the chance of a medical emergency that may make it difficult for an individual to make his or her own medical decisions, possibly leading to an unnecessarily prolonged and painful death (CDC, 2017a). Fortunately, a person may complete an advance directive (AD) and state in writing his or her preferences for care and appoint a durable power of attorney for healthcare (DPOAHC) to make medical decisions when that person does not have decision-making capacity; however, only 30% of Americans have completed this document (CDC, 2017a). Exploring the wishes of an older adult with chronic disease through an advance care planning (ACP) conversation elicits future patient wishes and preferences and may decrease future suffering for both patients and their caregivers (Sullivan & Dickerson, 2016). Advance care planning is the process of discussing a patient's medical wishes for serious illness or end-of-life care with the patient and family members and recording these wishes in ADs. This should be a recurring process and not a one-time discussion.

Statement of Problem

Advance care planning conversations and the presence of ADs are important as they increase the chances that a person's wishes about care with serious illness or at the end-of-life will be known and respected. ACP can include completing an AD such as a living will and/or DPOAHC. It also may include the completion of a Physician Order for Life Sustaining Treatment (POLST) or a Transportable Physician Order for Patient Preferences (TPOPP) form with medical orders reflecting a patient's preferences for care during an emergency or at end-of-life. Although most adults believe ACP conversations are important before they are seriously ill only 5-15% of physicians have this discussion with their patients (Sullivan & Dickerson, 2016). It is not the intention of any healthcare provider to cause a patient or family harm but avoiding ACP conversations indirectly causes harm (Bernacki & Block, 2014; Klindtworth et al., 2015). Advance care planning is associated with an improved quality of life (Meyers & Goodlin, 2016). The timely initiation of an ACP conversation increases the likelihood that a patient's wishes are known and documented with the hope that needless suffering can be averted (Chandar et al., 2017; Sullivan & Dickerson, 2016).

Heart failure is a terminal illness with a mortality rate of 50% within five years and 90% within 10 years of diagnosis (Audi et al., 2017). This outcome should compel cardiologists to talk with patients about what to expect in advancing illness (Audi et al., 2017); however, only 15% of cardiologists believe that it is their responsibility to handle ACP conversations for heart failure patients (Chandar et al., 2017). One study found that participants with fewer than two years to live did not understand the progression of heart failure or know that the disease is terminal (Hupcey, Kitko, & Alonso, 2016). These collective findings make prioritizing ACP conversations in this population important.

Heart failure is a common, complex disease, and as such, cardiology clinicians have created heart failure clinics within their larger cardiology practices. However, it is not common practice for most heart failure clinics to have a protocol for ACP to identify and engage appropriate patients earlier in the course of care. The purpose of this project was to develop a protocol to improve the process of increasing ACP conversations with patients with heart failure. The protocol was designed for providers who want to implement or improve ACP for persons with heart failure in an outpatient heart failure clinic. The entire protocol is available in Appendix A and a one-page algorithm of the project is available in Appendix B.

Background and Significance

Risk Factors for Heart Failure

Heart disease is currently the leading cause of death in the United States and remains the number one or two leading cause of death since 1910 (CDC, n. d.; CDC, 2017b). While heart failure is a subset of heart disease, many of the risk factors for heart failure are other forms of heart disease (Benjamin et al., 2017). Risk factors include coronary heart disease (CHD), hypertension (HTN), diabetes (DM), obesity and smoking. One third of Americans are classified as stage A heart failure, or those with predisposing risks for developing the disease (Benjamin et al., 2017).

Coronary heart disease. Coronary heart disease occurs when plaque builds up inside the vessels that supply the heart with blood (American Heart Association [AHA], 2018). Chronically, this can lead to a narrowing of the vessels, which can slowly decrease and eventually stop blood flow to the heart. Acutely, the plaque can break and cause an immediate cessation of blood flow to the heart. Both avenues lead to a myocardial infarction (AHA, 2018). Coronary heart disease affects 16.5 million Americans over 20, with a prevalence of 6.3%

(Benjamin et al., 2017). The direct and indirect cost of CHD was just short of \$200 billion in 2013; costs are projected to increase 100% by 2030 (Benjamin et al., 2017).

Hypertension. Hypertension is defined as a systolic blood pressure ≥ 140 mmHg or a diastolic blood pressure of ≥ 90 mmHg or reported use of an antihypertensive medication (Benjamin et al., 2017). The prevalence of HTN was estimated to be 34% from 2011-2014, affecting 85 million adults older than 20. While HTN does not cause death outright, it contributes to morbidity and mortality and is a risk factor for heart disease. Risk factors include age, race/ethnicity, family history, obesity, smoking, sleep apnea, and high intake of fat, sodium and alcohol. The lifetime risk of someone developing heart failure is 1.6 times greater for those with HTN compared to those without HTN (Benjamin et al., 2017).

Diabetes. A hemoglobin A1C $> 6.5\%$ or a fasting blood sugar > 126 mg/dL is indicative of diabetes. It is estimated that 9.4% of the population has diabetes, equating to 30.3 million people. Of those, 7.2 million of them have undiagnosed diabetes (CDC, 2017c). Furthermore, another 33.3% of Americans have prediabetes, which may progress into type 2 diabetes without lifestyle modifications (CDC, 2017c). Individuals with diabetes are more likely to develop heart disease and are two to four times more likely to die from heart disease than those without diabetes. In relation to heart failure, diabetes alone qualifies individuals for American Heart Association/American College of Cardiology (AHA/ACC) stage A heart failure (Benjamin et al., 2017). Studies have shown that those with diabetes are at increased risk of developing heart failure (Benjamin et al., 2017).

Obesity. Obesity is defined as a body mass index (BMI) of > 30.0 (Benjamin et al., 2017). Since 1999 the prevalence of obesity has continued to increase, and current data reveals that 37.7% of Americans are obese (Benjamin et al., 2017). Obesity is associated with chronic

health conditions such as DM, HTN, CHD, dyslipidemia, stroke, obstructive sleep apnea, as well as increased risk of mortality. The lifetime risk of developing heart failure for someone with a BMI > 30.0 is double compared to someone with a healthy BMI of < 25. While the risk factors for obesity are well known, many Americans do not perform the recommended amount of physical activity or eat according to dietary recommendations (Benjamin et al., 2017).

Smoking. Most recent estimates suggest that 16.7% of men and 13.7% of women over age 18 smoke (Benjamin et al., 2017). While this has decreased since 1965, it is still moderately high despite the knowledge that smoking is harmful to health. Smoking itself does not cause heart failure but is a risk factor for developing CHD (Benjamin et al., 2017). It also has a synergistic effect with HTN and diabetes, both of which increase the risk of heart failure. Smoking cessation is proven to reduce the risk of morbidity and mortality for those with and without cardiovascular disease (Benjamin et al., 2017).

Heart Failure Symptom Burden, Disease Trajectory and Patient Understanding

Within the past 10-15 years, the research literature has shown that heart failure patients have lower quality of life and a high symptom burden (Lewin & Schafer, 2017; Xu et al., 2015). Symptoms of heart failure include persistent dyspnea, pain, anxiety, fatigue, edema, nausea, altered mental status, insomnia and depression (Lewin & Schafer, 2017; Xu et al., 2015). As the disease progresses, many of the symptoms become refractory to treatment, increasing the symptom burden. A 2015 observational cross-sectional study by Xu and colleagues compared symptom burden and quality of life scores between patients diagnosed with amyotrophic lateral sclerosis, chronic obstructive pulmonary disease and heart failure and found those with heart failure had the lowest quality-of-life scores.

Three concerning themes occur in the literature: (1) patients with heart failure do not understand the disease and often blame their symptoms on old age or other comorbid conditions (Hupcey et al., 2016; Klindtworth et al., 2015); (2) patients do not understand this disease will progressively worsen over time and result in death (Glogowska et al., 2016; Hupcey et al., 2016; Klindtworth et al., 2015); and (3) caregivers do not understand the severity of the disease and cannot recognize when their loved one is dying (Alonso, Hupcey & Kitko, 2017). Further complicating these themes is the variable disease trajectory of heart failure. Lack of understanding and variable illness trajectory contributed to provider, patient, and caregiver overestimation of patient survival time (Alonso et al., 2017; Meyers & Goodlin, 2016). This impacted patient opportunity to discuss ACP with his or her provider (Glogowska et al., 2016).

Barriers to Advance Care Planning

Numerous barriers to ACP were identified in the literature. Resource barriers included lack of time, training, confidence in handling this difficult topic, knowledge regarding available tools and staff shortage (Dube, McCarron & Nannini, 2015; Waldrop & Meeker, 2012). Some barriers could be rectified with restructuring of appointments and training staff. However, the two barriers that were not easily overcome included the reluctance to discuss realistic prognosis and the clinician's attitude of "that isn't my problem." Clinicians and patients alike do not want to discuss death, and so each wait for the other to bring up the topic (Alonso et al., 2017; Hupcey et al., 2016; Meyers & Goodlin, 2016). Other providers, including cardiologists, considered treatment as their only responsibility or expected someone else would have the conversation, and so the topic was never broached (Chandar et al., 2017). Chandar and colleagues (2017) found this to be true for cardiologists; when compared to primary care physicians and oncologists, only 15% of cardiologists thought ACP conversations were their responsibility, 57% rarely or never

performed them, and 75% thought it was the job of the primary care physician. Finally, some clinicians did not broach the subject because they did not want to “take away hope” (Meyers & Goodlin, 2016). They feared a conversation about death and dying would increase anxiety, depression, and family distress (Bernacki & Block, 2014).

Benefits of Advance Care Planning

Benefits of ACP were well-documented. Timely ACP conversations are associated with reduced hospital admissions, decreased inappropriate healthcare usage, decreased cost of care in last year of life, and less aggressive care near death (Chandar et al., 2017; Meyers & Goodlin, 2016). ACP can decrease patient anxiety, increase satisfaction with care, improve quality of care, respect patient autonomy and dignity, and improve communication (Dube et al., 2015; Meyers & Goodlin, 2016; Weathers et al., 2016). Advance care planning is also beneficial to family members involved in the conversation as it lessens the burden of making a difficult decision by knowing what the person would choose for medical care. Knowing what the patient desires at his or her end-of-life gives caregivers more peace about making the right decision (Dube et al., 2015).

Changes in Reimbursement

Advance care planning conversations can be time-consuming. A significant and often-cited barrier to ACP was the lack of reimbursement for a process that could take considerable time (Sonenberg & Sepulveda-Pacsi, 2018). However, in January of 2016, Medicare eliminated this barrier and began paying for time spent performing ACP services (Moore & Hays, 2016). There are now two billing codes for this service: 99497 and 99498. A 99497 is for the first 30 minutes and includes discussing ADs and patient desires (Moore & Hays, 2016). The AD forms do not need to be completed to bill for the conversation. This conversation is flexible as it can be

performed by a physician, advanced practice registered nurse (APRN), physician assistant or registered nurse (RN), and billed during multiple encounters. It must be face-to-face, but it can be with the patient, family member(s), and/or surrogate (Moore & Hays, 2016; Sonenberg & Sepulveda-Pacsi, 2018). A 99498 is used for each additional 30 minutes of counseling time spent. The codes can be billed as a stand-alone visit or added onto a normal patient visit, but if it is added on it must be in addition to the evaluation and management time (Moore & Hays, 2016). The 99497 counts as 2.40 relative value units (RVUs), which is about \$85.99. The 99498 counts as 2.08 RVUs, about \$74.52 (Moore & Hays, 2016).

Advance Care Planning Across the Lifespan

It is estimated that 30-50% of middle aged to older adults have completed some form of AD (CDC, 2017a; Stevenson & O'Donnell, 2015). However, the rates are lower in patients with heart failure. A study examined 24,000 hospitalized patients with heart failure and found only 12.7% had a documented AD (Stevenson & O'Donnell, 2015). Patients were found to be seven times more likely to complete an AD if an ACP discussion took place (Van Scoy et al., 2016).

Clinicians often fear that having an ACP conversation will increase anxiety, depression and take away hope; however, the literature shows this fear is lacking in evidence (Bernacki & Block, 2014). Nevertheless, repeated qualitative studies with patients and caregivers alike echo frustration with providers for a lack of open communication about these topics (Fitzsimmons et al., 2019; Gusdal, Josefsson, Adolfsson & Martin, 2016; Klindtworth et al., 2015; Stevenson & O'Donnell, 2015). Many patients feel open communication is not provided and are not satisfied with their care in this area (Apatira et al., 2008; Klindtworth et al., 2015). The progression of the disease and recurrent exacerbations should trigger a patient and family needs assessment (Meyers & Goodlin, 2016).

Advance Care Planning with Heart Failure Patients

The variability of heart failure disease progression makes it difficult for clinicians to know when the “right time” is to have ACP discussions (Meyers & Goodlin, 2016). In a systematic review, Meyers and Goodlin noted that 50% of heart failure patients stated they would prefer to receive terminal care at home, but only 25% had that opportunity. Klindtworth et al. (2015) discovered a similar theme; older patients wished for a quick, peaceful death and desired to die at home. Death at home was not discussed as an option for patients.

In any patient population, most ACP conversations occur late in the progression of the disease, often when treatment options are no longer available or effective (Chandar et al., 2017). However, most heart failure patients die before reaching end-stage heart failure (Whellan et al., 2014). Patient-centered care includes communicating with patients about their values and goals and explaining interventions that align with those goals (Whellan et al., 2014). Completing ACP early during the disease prepares patients and families for effective decision making for the overall course of the disease and possible future device treatments, such as pacemaker or implantable cardio-defibrillator (ICD) placement (Waldrop & Meeker, 2012).

Project Aims

This quality improvement project developed and evaluated an evidence-based protocol for use in an outpatient heart failure clinic to improve the ACP process. This process was created by performing a literature and resource review, evaluating and analyzing the findings, and using clinical experts as reviewers.

Theoretical Framework

The theoretical framework for this project is the Trajectory Model by Corbin and Strauss (Robinson et al., 1993). Corbin, a nurse, and Strauss, a social scientist, developed this model after over 30 years of research in chronic illness management (Robinson et al., 1993).

“Trajectory” is the main concept and encompasses all aspects of an individual having a chronic illness, not only the physical (Robinson et al., 1993). “Biography” is an individual’s identity, including his or her past experiences and how those affect his or her choices today. “Trajectory projection” is the future of the illness and the course it generally takes. The model has nine phases that reflect the various stages an individual will experience while having a chronic disease (Corbin, 1998). This model accounts for the difficulties that arise in managing chronic illness and what individuals experience while adjusting to their illness. This theory is well-matched for heart failure because the nine phases of the theory reflect an individual’s disease trajectory through heart failure and account for the extreme variability of each patient. This theory is appropriate for ACP because the theory concludes with the dying process and acknowledgement of death (Robinson et al., 1993).

Methods

Design

A review of the literature was performed to assess current evidence for ACP protocols and associated subjects. After the literature search, the evidence was analyzed, evaluated and synthesized by using a matrix, and then developed into a protocol. Two cardiology providers evaluated the protocol using a modified Appraisal of Guidelines for Research and Evaluation II (AGREE II) tool. They were also asked additional qualitative questions regarding implementation feasibility, protocol usefulness, and suggestions for improvements. The feedback from the evaluation was analyzed and necessary changes made to the protocol.

Human Subject Protection

Institutional Review Board (IRB) approval was obtained from University of Kansas Medical Center before beginning this project. Informed consent was not sought because this is a quality improvement project and no patient information was collected. Protocol evaluation was

performed by two providers in separate outpatient cardiology clinics who were willing to assist in the project. There was no direct interaction with patients. Information obtained during the evaluation phase was kept on a secure computer at University of Kansas Medical Center.

Literature Search and Strategy

A literature search was performed between September 2018 and January 2019 using databases including CINAHL, PubMed, Cochrane, and Medline. Keywords for the literature search consisted of advanced care planning, end-of-life conversations, advanced directives, heart failure, congestive heart failure, cardiac failure, chronic heart failure, living wills, end-of-life wishes, protocol, guidelines, procedure, practice, policy, implementation strategies, and quality improvement. Higher level of evidence articles (meta-analysis, randomized controlled trials) were sought and given preference over lower evidence articles (expert opinion, case study). Article inclusion criteria consisted of English language, full text available and the initial search was limited to the past five years. The search was extended to 20 years, yet no articles focused on implementing or creating protocols to increase ACP conversations. A matrix was created to assess evidence quality and assist in evidence synthesis.

Search Results

A total of 1,833 articles were identified using the search terms; however, no articles focused on implementing or creating pathways/protocols to increase ACP conversations in outpatient clinics. Three articles proposed timing of ACP conversations with heart failure patients; one a consensus statement from the AHA (Allen et al., 2012), and two editorials, one of which referenced the AHA article and other editorial (Dunlay & Strand, 2016; Lum & Sudore, 2016). Eighty-seven articles were chosen from the 1,833 articles identified during the literature search. These articles were full text and selected based on title and abstract information that

included advanced care planning information such as implementation, barriers, advantages, finances, administration and tools and heart failure information including ACP in the heart failure population, billing and coding, caregiver and patient perception of heart failure and disease trajectory. The articles reviewed fell into 6 categories or a combination of: 1) general ACP information (barriers, benefits, documentation, etc.) and its importance; 2) the difficulties of performing ACP in the heart failure population; 3) patient and caregiver understanding of heart failure and/or ACP; 4) clinician perception of ACP and its difficulties; 5) increasing/evaluating ACP through a specific tool/intervention; 6) and implementing palliative care into heart failure. Article evaluation through matrix use included those that assessed increasing ACP through a specific tool/intervention (Appendix C).

Protocol Evaluation

Protocol Evaluators

After the protocol was developed, cardiology providers were invited to evaluate the rigor, clarity, and applicability of the protocol using a modified AGREE II tool. In addition, the providers were asked for their opinion regarding the feasibility of implementing the protocol in their clinic. These providers were selected from a convenience sample known to the project director.

Three cardiology providers were asked to participate in the project and all accepted. Each provider was from a different outpatient cardiology clinic. There were no stipulations regarding size of practice, provider title (M.D., N.P., P.A.), how many providers are at the practice, or how many patients the provider cares for daily. Clinicians were contacted in January of 2019 via email. The email included an explanation of the project and inquired if he/she was willing to participate in evaluating the protocol. After the quality improvement protocol was finalized, a

reiteration of the project, the protocol, and an explanation of the modified AGREE II tool was sent to the participants.

Protocol Evaluation Tool

The AGREE tool was developed to provide clinicians with an instrument to methodologically assess practice guideline quality (AGREE Next Steps Consortium, 2017). An international team of guideline developers and researchers developed the first tool in 2003 and made updates in 2009, creating the AGREE II tool (Brouwers et al., 2010). Any provider can use the AGREE II tool. It takes about 1.5 hours to complete and comes with a manual to assist the appraiser during the review process. It is recommended that at least two, but preferably four, appraisers review the guideline in question (Brouwers et al., 2010). The AGREE II focuses on the methodological issues present during guideline development and is unable to evaluate the validity guideline recommendation validity (Brouwers et al., 2010). This is a target point of the next phase of AGREE tool development. The AGREE II is a 23-item questionnaire that uses a 7-point Likert scale and is divided into 6 domains (Brouwers et al., 2010).

The AGREE II manual has information on how to score the document in question and interpret those scores. Once all appraisers score the document using the Likert scales the data is added together by domain and then converted into percentages by using the maximum possible score for that domain (AGREE Next Steps Consortium, 2017). This is dependent upon how many appraisers score the document and if all the questions are used in each domain. It is suggested by the manual to use a cut off > 70% for high quality documents. See page nine in the AGREE Next Steps Consortium instruction manual (2017) for a complete analysis.

The percentages should not be combined into a single overall score but should remain separate by domain (AGREE Next Steps Consortium, 2017). There are several different ways to

interpret the domain scores once a percentage is obtained for each. The first way is to prioritize one domain over others. This can be decided based on consensus between those appraising the document or predetermined by an individual directing the guideline review. The second way is to consider all domain scores, i.e. the document must score > 70% in all domains to be considered high quality. The third way is to evaluate for percentage changes over time by comparing the guideline in question to its older counterpart (AGREE Next Steps Consortium, 2017).

The original AGREE II tool was modified to fit the purposes of this quality improvement project. Each question was evaluated for its applicability to this project and either removed or edited as needed. “Guideline” was changed to “protocol” on the scoring sheet. The user manual has information on what to consider and criteria used to score each item. The original numbers for each item were kept, assisting evaluators in using the manual and modified scoring sheet together. The purpose of using this tool was to obtain a quantitative evaluation of the protocol and assess for areas of improvement. Permission was not obtained as the AGREE tool can be modified with proper citation as noted on the AGREE Enterprise website (AGREE, n.d.). The modified AGREE II tool scoring sheet can be found in Appendix D.

Protocol Evaluation Process

Protocol evaluation was conducted through both quantitative and qualitative methods. The quantitative information was obtained using the modified AGREE II tool. The qualitative information was obtained using a self-developed questionnaire regarding protocol feasibility (Appendix E). In addition, demographic characteristics of protocol evaluators were also collected, including title, years of experience as a cardiology provider, location of clinic (rural vs. metropolitan), age and gender (Appendix E).

After the modified AGREE II was returned it was scored and the scores were compared between providers. If scores had a difference of greater than 20% an assessment would have been conducted. Areas with the lowest scores were evaluated for possibility of improvement. The questionnaire for protocol feasibility was reviewed and analyzed by the project coordinator without identifying changes needed in the protocol.

Results of Protocol Evaluation

Evaluator Demographics

Three cardiology providers were asked to evaluate the protocol and all three accepted. A time frame of one month was given for reviewing and scoring the protocol. A reminder email was sent to the evaluators one week before the deadline. Two of the three evaluators returned their completed information to the project coordinator within the specified time frame. The project coordinator contacted the third provider without response.

Both evaluators were APRNs in separate practices in a metropolitan area. Evaluator A was male, age 37 with five years of experience in a large heart failure clinic serving more than 1800 heart failure patients. Evaluator B was female, age 45 with 20 years of experience in cardiology and coordinated a heart failure clinic for 400 patients.

Modified AGREE II Results

Scores were calculated by the project coordinator. Both evaluator Likert scores were added together by domain and converted to percentages by using the maximum possible score for that domain. Full scoring instructions can be found in the AGREE II user manual (AGREE Next Steps Consortium, 2017). A score of >70% in all domains was considered high quality. The scores for each domain are as follows:

Domain 1: Scope and Purpose 90%

Domain 2: Stakeholder Involvement 88%

Domain 3: Rigor of Development 86%

Domain 4: Clarity of Presentation 79%

Domain 5: Applicability 92%

A comparison between the two evaluators showed similar scores given in each domain.

The scores did not differ by more than 20%, therefore further assessment did not need to be conducted.

Questionnaire Results

Four questions were asked the providers.

- 1) How feasible would protocol implementation be in your clinic?
- 2) How could the protocol be made stronger/more complete?
- 3) What are the barriers you see to implementing a protocol such as this?
- 4) Do you think the protocol would be useful in your clinic?

Both evaluators agreed protocol implementation would be feasible in a heart failure clinic but would be more achievable in a small setting because of patient volume. Neither evaluator shared suggestions to improve the protocol. Identified barriers included administration, additional support staff time needed to identify and schedule patients, and length of appointment times needed for ACP discussions. Despite the barriers, both evaluators felt that the protocol would be useful in their respective clinics.

Discussion

Through an evidenced based literature search data was gathered, analyzed and synthesized into the development of this protocol. Protocol evaluation occurred through two independent cardiology providers using the modified AGREE II tool and a qualitative questionnaire. A score of > 70% was considered high quality for the original AGREE II tool, and this standard was used for the modified AGREE II tool as well. Using the modified tool, each domain received a score of > 70%. This was higher than expected and the limitations discussed below factor into the scores.

Domain 4: Clarity of presentation received the lowest score. In the original AGREE II tool, there are three items in this domain. For this project, one item was removed due to applicability. This domain scored lower because of the imprecise nature of this topic, the individuality of each patient situation, provider style and resource availability. It would be difficult to give specific recommendations when patient-care should be tailored to individual need. The protocol contains high level recommendations but breaks down when specific situations are generated.

Domain 5: Applicability scored the highest with 92%. The original AGREE II tool has four items in this domain and was one removed for the modified tool. This domain considers the barriers and benefits of implementation, tools and advice on how to put recommendations into practice and resource issues that could potentially arise with implementation (AGREE Next Steps Consortium, 2017). This domain scored the highest because the protocol contains strategies and tool for implementation, training methods for additional provider education, and resources for commonly occurring barriers.

Limitations

The AGREE II tool recommends using two to four evaluators to score a guideline, with favor given to including more evaluators. We attempted to include three evaluators for this protocol; however, given time constraints one of the evaluators who originally agreed to participate was not able to complete the task. Having more evaluators would improve the review process. This may have skewed the results of the modified AGREE II tool, contributing to the higher than expected domain scores. This could be due to the theoretical nature of the project. If tasked with implementation, other providers would more than likely find ways to strengthen the protocol. Other limitations of protocol evaluation include similar clinic locations, convenience sampling and the professional relationship between the project coordinator and evaluators.

Project Improvements and Future Plans

One way this protocol could be improved upon is the application of an EMR to the process. The EMR could be utilized in a variety of ways, including triggering alerts for patients who do not have an AD, or who meet other stipulations decided by the project coordinator (recent hospitalizations/ER visits, late stage AHA/ACC classes, continued increases in diuretics, etc.), placing the AD in a common place all providers can find, or compiling a list of all patients needing ACP conversations. An additional way this protocol could be improved upon is in its evaluation: including more evaluators from different disciplines, different geographies, and with a different sampling method.

Currently there is no plan for implementation; however, this author would be supportive of any student (or provider) desiring to implement it as a QI project and is amenable to any adaptations needed for implementation. The author will discuss this opportunity with Doctor of Nursing Practice students he encounters in the future.

Summary

There is clear agreement in the literature that ACP is important for patients and providers. There are no published studies on implementing ACP protocols in heart failure or primary care clinics, yet there is a growing awareness and interest in improving conversations and aligning goals with treatments. A protocol can be a starting point or resource for improving the process of identifying and implementing ACP in a heart failure clinic. This protocol must be used with a small, committed team of healthcare providers willing to begin this conversation with patients. There is so much about medicine that patients and family members do not understand, and we as healthcare providers need to do better, be better, for our patients. The goal guiding this project was to improve quality of life for heart failure patients through ACP. This protocol was created to begin this process, in the hopes that it, or something similar, would be implemented in a heart failure clinic, improving ACP for patients and providers alike.

References

Agency for Healthcare and Quality Research. (2017a). *About TeamSTEPPS*.

<https://www.ahrq.gov/teamstepps/about-teamstepps/index.html>

Agency for Healthcare and Quality Research. (2017b). *The CAHPS ambulatory care improvement guide: Practical strategies for improving patient experience*.

<https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/improvement-guide.html>

Aging with Dignity. (2018). *Five wishes*. <https://fivewishes.org/Home>

AGREE. (n.d.). *Frequently asked questions*. <https://www.agreetrust.org/about-the-agree-enterprise/frequently-asked-questions/>

AGREE Next Steps Consortium. (2017). The AGREE II Instrument [Electronic version].

Retrieved November,5, 2018, from <http://www.agreetrust.org>.

Allen, L. A., Stevenson, L. W., Grady, K. L., Goldstein, N. E., Matlock, D. D., Arnold, R. M. ...

& Spertus, J. A. (2012). Decision making in advanced heart failure: A scientific statement from the American Heart Association. *Circulation*, 125, 1928-1952. doi: 10.1161/CIR.0b013e31824f2173

Alonso, W., Hupcey, J. E., & Kitko L. (2017). Caregivers' perceptions of illness severity and end

of life service utilization in advanced heart failure. *Heart and Lung*, 46, 35-39. doi: 10.1016/j.hrtlng.2016.09.001

American Heart Association. (2018). *Coronary artery disease-coronary heart disease*.

http://www.heart.org/HEARTORG/Conditions/More/MyHeartandStrokeNews/Coronary-Artery-Disease%20%80%94Coronary-Heart-Disease_UCM_436416_Article.jsp#.XJhQSShKhPY

Apatira, L., Boyd, E. A., Malvar, G., Evans, L. R., Luce, J. M., Lo, B., & White, D. B. (2008).

- Hope, truth, and preparing for death: Perspectives of surrogate decision makers. *Annals of Internal Medicine*, 149, 861-868. doi: 10.7326/0003-4819-149-12-200812160-00005
- Ariadne Labs. (2017). *Talking with your clinician about the future*.
https://portal.ariadnelabs.org/?get_group_doc=1/1522703211-Pre-VisitLetter_Updated10.30.15.pdf
- Audi, G., Korologou, A., Koutelekos, I., Vasilopoulos, G., Karakostas, K., Makrygianaki, K., & Polikandrioti, M. (2017). Factors affecting health related quality of life in hospitalized patients with heart failure. *Cardiology Research and Practice*, 20, 1-12. doi: 10.1155/2017/4690458
- Ba, K. X., Gelfman, L., Horton, J. R., & Goldstein, N. E. (2017). State of research on palliative care in heart failure as evidenced by published literature, conference proceedings, and NIH funding. *Journal of Cardiac Failure*, 23, 197-200. doi: 10.1016/j.cardfail.2016.10.013
- Benjamin, E. J., Blaha, M. J., Chiuve, S. E., Cushman, M., Das, S. R., Deo, R., ... & de Ferranti, S. D. (2017). Heart disease and stroke statistics—2017 update. *Circulation*, 135, 146-603. doi: 10.1161/CIR.0000000000000485
- Bernacki, R. E. & Block, S. D. (2014). Communication about serious illness care goals: A review and synthesis of best practices. *Journal of the American Medical Association Internal Medicine*, 174, 1994-2003. doi: 10.1001/jamainternmed.2014.5271
- Bernacki, R. E., Hutchings, M., Vick, J., Smith, G., Paladino, J., Lipsitz, S. ... & Block, S. D. (2015). Development of the Serious Illness Care Program: A randomized controlled trial of palliative care communication intervention. *The British Journal of Medicine Open*, 5. doi:10.1136/bmjopen-2015-009032
- Brouwers, M. C., Kho, M. E., Browman, G. P., Burgers, J. S., Cluzeau, F., Feder, G., ... &

- Zitzelsberger, L. (2010). AGREE II: Advancing guideline development, reporting and evaluation in health care. *Canadian Medical Association Journal*, 182, 839-842. doi: 10.1503/cmaj.090449
- Centers for Disease Control and Prevention. (n.d.) *Leading causes of death, 1900-1998*.
https://www.cdc.gov/nchs/data/dvs/lead1900_98.pdf
- Centers for Disease Control and Prevention. (2016). *Heart failure fact sheet*. https://www.cdc.gov/dhdsp/data_statistics/fact_sheets/fs_heart_failure.htm
- Centers for Disease Control and Prevention. (2017a). *Give peace of mind: Advance care planning*. <https://www.cdc.gov/aging/advancecareplanning/index.htm>
- Centers for Disease Control and Prevention. (2017b). *Leading causes of death*.
<https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>
- Centers for Disease Control and Prevention. (2017c). *National diabetes statistics report, 2017: Estimates of diabetes and its burden in the United States*. <http://www.diabetes.org/assets/pdfs/basics/cdc-statistics-report-2017.pdf>
- Center to Advance Palliative Care. (2019). *About the Center to Advance Palliative Care*.
<https://www.capc.org/about/capc/>
- Chandar, M., Brockstein, B., Zunamon, A., Silverman, I., Dlouhy, S., Ashlevitz, K., ... & Obel, J. (2017). Perspectives of health-care providers toward advanced care planning in patients with advanced cancer and congestive heart failure. *American Journal of Hospice and Palliative Medicine*, 34, 423-429. doi:10.1177/1049909116636614
- Chen-Scarabelli, C., Saravolatz, L., Hirsh, B., Agrawal, P., & T. M. Scarabelli. (2015). Dilemmas in end-stage heart failure. *Journal of Geriatric Cardiology*, 12, 57-65. doi: 10.11909/j.issn.1671-5411.2015.01.007

Colorado Program for Patient Centered Decisions. (2019). *Facing a difficult medical decision?*

<https://patientdecisionaid.org/>

Corbin, J. M. (1998). The Corbin and Strauss chronic illness trajectory model: An update.

Scholarly Inquiry for Nursing Practice: An International Journal, 12, 33-41.

Davies, S. (2017). Coding discussions about the elephant in the room. *Journal of the American*

Health Information Management Association, 88, 72-73. [http://web.b.ebscohost.](http://web.b.ebscohost.com.proxy.kumc.edu:2048/ehost/pdfviewer/pdfviewer?vid=6&sid=12053840-27f4-4a1c-9c5d-3e75bfe1e320%40sessionmgr104)

[com.proxy.kumc.edu:2048/ehost/pdfviewer/pdfviewer?vid=6&sid=12053840-27f4-4a1c-9c5d-3e75bfe1e320%40sessionmgr104](http://web.b.ebscohost.com.proxy.kumc.edu:2048/ehost/pdfviewer/pdfviewer?vid=6&sid=12053840-27f4-4a1c-9c5d-3e75bfe1e320%40sessionmgr104)

Department of Health and Human Services Health Resources and Services Administration.

(2011). *Quality improvement*. [https://www.hrsa.gov/sites/default/files/quality](https://www.hrsa.gov/sites/default/files/quality/toolbox/508pdfs/qualityimprovement.pdf)
[y/toolbox/508pdfs/qualityimprovement.pdf](https://www.hrsa.gov/sites/default/files/quality/toolbox/508pdfs/qualityimprovement.pdf)

Dingfield, L. E. & Kayser, J. B. (2017). Integrating advance care planning into practice. *Chest*,

151, 1387-1393. doi: 10.1016/j.chest.2017.02.024

Dixon, J. & Knapp, M. (2018). Whose job? The staffing of advance care planning support in

twelve international healthcare organizations: A qualitative interview study. *BioMed Central Palliative Care*, 17. doi: 10.1186/s12904-018-0333-1

Downar, J., Goldman, R., Pinto, R., Englesakis, M. & Adhikari, N. K. (2017). The “surprise

question” for predicting death in seriously ill patients: A systematic review and meta-analysis. *The Canadian Medical Association Journal*, 189, 484-493. doi:

10.1503/cmaj.160775

Dube, M., McCarron, A., & Nannini, A. (2015). Advanced care planning complexities for nurse

practitioners. *The Journal for Nurse Practitioners*, 11, 766-773. doi: 10.1016/j.nurpra.2015.05.011

- Dunlay, S. M., Foxen, J. L., Cole, T., Feely, M. A., Loth, A. R., Strand, J. J. ... & Redfield, M. M. (2015). A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. *Palliative Medicine*, 29, 260-267. doi: 10.1177/0269216314556565
- Dunlay, S. M. & Strand, J. J. (2016). How to discuss goals of care with patients. *Trends in Cardiovascular Medicine*, 26, 36-43. doi: 10.1016/j.tcm.2015.03.018
- El-Jawahri, A. E., Paasche-Orlow, M. K., Matlock, D., Stevenson, L. W., Lewis, E. F., Stewart, G. ... & Volandes, A. E. (2016). Randomized, controlled trial of an advance care planning video decision support tool for patients with advanced heart failure. *Circulation*, 134, 52-60. doi: 10.1161/CIRCULATIONAHA.116.02193
- Fitzsimons, D., Doherty, L. C., Murphy, M., Dixon, L., Donnelly, P., McDonald, K. & McIlfatrick, S. (2019). Inadequate communication exacerbates the support needs of current and bereaved caregivers in advanced heart failure and impedes shared decision-making. *Journal of Cardiovascular Nursing*, 34, 11-19. doi: 10.1097/JCN.0000000000000516
- Gange, J. J., Glynn, R. J., Avorn, J., Levin, R. & Schneeweiss, S. (2011). A combined comorbidity score predicted mortality in elderly patients better than existing scores. *Journal of Clinical Epidemiology*, 64, 749-759. doi: 10.1016/j.jclinepi.2010.10.004
- Glogowska, M., Simmonds, R., McLachlan, S., Cramer, H., Sanders, T., Johnson, R., ... & Purdy, S. (2016). "Sometimes we can't fix things": A qualitative study of health care professionals' perceptions of end of life care for patients with heart failure. *BioMed Central Palliative Care*, 15, 1-10. doi: 10.1186/s12904-016-0074-y
- Gusdal, A. K., Josefsson, K., Adolfsson, E.T. & Martin, L. (2016). Informal caregivers'

- experiences and needs when caring for a relative with heart failure: An interview study. *Journal of Cardiovascular Nursing*, 31, 1-8. doi: 10.1097/JCN.0000000000000210
- Hickman, R. L., Lipson, A. R., Pinto, M. D. & Pignatiello, G. (2014). Multimedia decision support intervention: A promising approach to enhance the intention to complete an advance directive among hospitalized adults. *Journal of the American Association of Nurse Practitioners*, 26, 187-193. doi: 10.1002/2327-6924.12051
- Hupcey, J. E., Kitko, L., & Alonso, W. (2016). Patients' perceptions of illness severity in advanced heart failure. *Journal of Hospice & Palliative Nursing*, 18, 110-114. doi:10.1097/NJH.0000000000000229
- Institute for Healthcare Improvement. (2018a). *How to improve*. <http://www.ihl.org/resources/Pages/HowtoImprove/default.aspx>
- Institute for Healthcare Improvement. (2018b). *The conversation project*. <https://theconversationproject.org/>
- Klindtworth, K., Oster, P., Hager, K., Krause, O., Bleidorn, J., & Schneider, N. (2015). Living with and dying from advanced heart failure: Understanding the needs of older patients at the end of life. *BioMed Central Geriatrics*, 15, 1-11. doi: 10.1186/s12877-015-0124-y
- Lakin, J. R., Koritsanszky, L. A., Cunningham, R., Maloney, F. L., Neal, B. J., Paladino, J. ... & Bernacki, R. E. (2017). A systematic intervention to improve serious illness communication in primary care. *Health Affairs*, 7, 1258-1264. doi: 10.1377/hlthaff.2017.0219
- Levy, W. C., Mozaffarian, D., Linker, D. T., Sutradhar, S. C., Anker, S. D., Cropp, A. B., ... & Packer. (2006). The Seattle heart failure model: Prediction of survival in heart failure. *Circulation*, 113, 1424-1433. doi: 10.1161/CIRCULATIONAHA.105.584102
- Lewin, W. H. & Schaefer, K. G. (2017). Integrating palliative care into routine care of patients with heart failure: Models for clinical collaboration. *Heart Failure Reviews*, 22, 517-524.

doi:10.1007/s10741-017-9599-2

Lum, H. D., Barnes, D. E., Katen, M. T., Shi, Y., Boscardin, J. & Sudore, R. L. (2018).

Improving a full range of advance care planning behavior change and action domains:

The PREPARE randomized trial. *Journal of Pain and Symptom Management*, 56, 575-

581. doi: 10.1016/j.jpainsymman.2018.06.007

Lum, H. D., Jones, J., Matlock, D. D., Glasgow, R. E., Lobo, I., Levy, C. R. ... & Kutner, J. S.

(2016). Advance care planning meets group medical visits: The feasibility of promoting

conversations. *Annals of Family Medicine*, 14, 125-132. doi: 10.1370/afm.1906

Lum, H. D. & Sudore, R. L. (2016). Advance care planning and goals of care communication in

older adults with cardiovascular disease and multi-morbidity. *Clinical Geriatric*

Medicine, 32, 247-260. doi:10.1016/j.cger.2016.01.011

Lunney, J. R., Lynn, J., & Hogan, C. (2002). Profiles of older Medicare decedents. *The Journal*

of the American Geriatrics Society, 50, 1108-1112. doi: 10.1046/j.1532-

5415.2002.50268.x

Making Your Wishes Known. (2013). *Plan for your future*. <https://www.makingyourwishes>

[known.com/](https://www.makingyourwishesknown.com/)

McIlvennan, C. K. (2017). Improving decision making for advanced heart failure patients and

caregivers. *Journal of Nursing Administration*, 47, 190-191. doi:

10.1097/NNA.0000000000000463

Meyers, D. E. & Goodlin, S. J. (2016). End-of-Life decisions and palliative care in advanced

heart failure. *Canadian Journal of Cardiology*, 32, 1148-1156. doi:10.1016/j.cjca.

2016.04.015

Moore, K. & Hays, B. (2016). Coding and billing rules in 2016: Out with the old, in with the

- new. *Family Practice Management*, 23, 14-16.
- Moore, Q. (2017). TeamSTEPPS: Addressing imaging procedure appropriateness. *Radiologic Technology*, 88, 50-555. <http://web.b.ebscohost.com.proxy.kumc.edu:2048/ehost/pdfviewer/pdfviewer?vid=7&sid=36d7881a-04f5-4b57-9822-00f724f4b565%40sessionmgr120>
- Moran, K. J., Burson, R., & Conrad, D. (2017). *The doctor of nursing practice scholarly project: A framework for success* (2nd ed.). Burlington, MA: Jones & Bartlett Learning.
- Myers, J., Cosby, R., Gzik, D., Harle, I., Harrold, D., Incardona, N. & Walton, T. (2018). Provider tools for advance care planning and goals of care discussions: A systematic review. *American Journal of Hospice & Palliative Medicine*, 35, 1123-1132. doi: 10.1177/1049909118760303
- PREPARE for your care. (2018). *PREPARE for your care*. <https://prepareforyourcare.org/welcome>
- Reidy, J., Halvorson, J., Makowski, S., Katz, D., Weinstein, B., McCluskey, C., ... & Tija, J. (2017) Health system advance care planning culture change for high-risk patients: The promise, and challenges of engaging providers, patients, and families in systematic advance care planning. *Journal of Palliative Medicine*, 20, 388-394. doi: 10.1089/jpm.2016.0272
- Robinson, L. A., Bevil, C., Arcangelo, V., Reifsnnyder, J., Rothman, N., & Smeltzer, S. (1993). Operationalizing the Corbin & Strauss trajectory model for elderly clients with chronic illness. *Scholarly Inquiry for Nursing Practice: An International Journal*, 7, 253-264.
- Sadeghi, B., Walling, A. M., Romano, P. S., Ahluwalia, S. C. & Ong, M. K. (2016). A hospital-

- based advance care planning intervention for patients with heart failure: A feasibility study. *Journal of Palliative Medicine*, 19, 451-455. doi: 10.1089/jpm.2015.0269
- Silver, S. A., Harel, Z., McQuillian, R., Weizman, A. V., Thomas, A., Chertow, G. M., ... & Chan, C. T. (2016). How to begin a quality improvement project. *Clinical Journal of the American Society of Nephrology*, 11, 893-900. doi: 10.2215/CJN.1149101
- Sonenberg, A. & Sepulveda-Pacsi, A. L. (2018). Medicare payment: Advanced care planning. *The Journal for Nurse Practitioners*, 14, 112-116. doi: 10.1016/j.nurpra.2017.11.023
- Stevenson, L. W., & O'Donnell, A. (2015). Advanced care planning: Care to plan in advance. *Journal of the American College of Cardiology: Heart Failure*, 122-126. doi: 10.1016/j.jchf.2014.09.005.
- Sudore, R. L., Boscardin, J., Feuz, M. A., McMahan, R. D., Katen, M. T. & Barnes, D. E. (2017). Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans: A randomized clinical trial. *Journal of the American Medical Association Internal Medicine*, 177, 1102-1109. doi: 10.1001/jamainternmed.2017.1607
- Sudore, R. L., Landefeld, C. S., Barnes, D. E., Lindquist, K., Williams, B. A., Brody, R. & Schillinger, D. (2007). An advance directive redesigned to meet the literacy level of most adults: A randomized trial. *Patient Education and Counseling*, 69, 165-195. doi: 10.1016/j.pec.2007.08.015
- Sullivan, S. S. & Dickerson, S. S. (2016). Facing death: A critical analysis of advanced care planning in the United States. *Advances in Nursing Science*, 39p, 320-332. doi: 10.1097/ANS.0000000000000138
- Treece, J., Chemchirian, H., Hamilton, N., Jbara, M., Gangadharan, V., Paul, T., & Baumrucker, S. J. (2017). A review of prognostic tools in heart failure. *American Journal of Hospice*

- and Palliative Medicine*, 35. doi:10.1177/1049909117709468
- University of Washington. (2017). *Seattle heart failure model*. <https://depts.washington.edu/shfm/?width=1536&height=864>
- Van Scoy, L. J., Green, M. J., Dimmock, A., Bascom, R., Boehmer, J. P., Hensel, J. K., ... & Levi, B. H. (2016). High satisfaction and low decisional conflict with advanced care planning among chronically ill patients with advanced chronic obstructive pulmonary disease or heart failure using an online decision aid: A pilot study. *Chronic Illness*, 12, 227-235. doi: 10.1177/1742395316633511
- Vital Talk. (2018). *Clinicians*. <http://vitaltalk.org/clinicians/>
- Waldrop, D. P. & Meeker, M. A. (2012). Communication and advanced care planning in palliative and end-of-life care. *Nursing Outlook*, 60, 365-369. doi: 10.1016/j.outlook.2012.08.012
- Weathers, E., O' Caoimh, R., Cornally, N., Fitzgerald, C., Kearns, T., Coffey, A., ... & Molloy, D. W. (2016). Advanced care planning: A systematic review of randomized controlled trials conducted with older adults. *Maturitas*, 91, 101-109. doi: 10.1016/j.maturitas.2016.06.016
- Whellan, D. J., Goodlin, S. J., Dickinson, M. G., Heidenreich, P. A., Jaenicke, C., Stough, W. G., & Rick, M. W. (2014). End-of-life care in patients with heart failure. *Journal of Cardiac Failure*, 20, 121-134. doi: 10.1016/j.cardfail.2013.12.003
- White, N., Kupeli, N., Vickerstaff, V. & Stone, P. (2017). How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. *BioMed Central Medicine*, 15. doi: 10.1186/s12916-017-0907-4
- Xu, J., Nolan, M. T., Heinze, K., Yenokyan, G., Hughes, M. T., Johnson, J., ... & Lee, M. C. (2015). Symptom frequency, severity and quality of life among persons with three

disease trajectories: Cancer, ALS and CHF. *Applied Nursing Research*, 28, 311-315. doi:
10.1016/j.apnr.2015.03.005

Zaccagnini, M. E. & White, K. W. (2017). *The doctor of nursing practice essentials: A new model for advanced practice nursing* (3rd ed.). Burlington, MA: Jones & Bartlett Learning.

Appendix A

A Protocol to Increase Advance Care Planning Conversations in an Outpatient Heart Failure Clinic

Assessment of Clinic

The assessment of the clinic is one of the most important parts of this process, as it will guide much of the QI project after the findings are reviewed. There may be more than one area needing improvement to facilitate ACP conversations. It may be possible to make all the changes at one time, or the changes may need to occur in steps. This will depend on the local environment of the clinic where the QI project is taking place. Clinic assessment consists of a chart review, informal interviews with providers, and reviewing clinic processes regarding ACP. This protocol is being developed for heart failure clinics, and as such, only patients with heart failure should be used for inclusion for the chart review. Initially, the entire clinic does not have to be included in the QI project. Choose a few providers who are willing to participate, and after the results are reviewed and improvements made the project can be expanded.

Chart Review. Advance care planning documentation and ADs have been used in the literature as a proxy for ACP conversations (Lum et al., 2018; Sudore et al., 2017). Using an electronic medical record, perform a chart audit for ACP documentation and the number of times ACP was billed by providers. Advance care planning documentation includes AD, a living will, DPOAHC, or TPOPP forms, and documented ACP discussions. The billing codes of 99497 and 99498 indicate ACP billed by providers. Limit the search results to AD documentation received in the clinic. This chart review should occur at baseline and then at the end of the QI project. For example, if a period of six months is chosen for the QI project, then the retrospective chart review should go back six months for baseline data. After 6 months of implementation, the chart review can be completed again to compare results.

Provider Interviews. An in-person interview should be performed with the providers participating in the QI project to assess how he or she performs ACP conversations and what triggers the provider to purposefully have a conversation. This author has created a questionnaire (Appendix F) to facilitate the interview which focuses on provider comfort, perception of appropriate timing, and format of ACP conversations he or she currently performs. Have the questionnaire present during the interview and record the answers on the sheet. At the end of the interview give the provider the opportunity to examine the document for accuracy and make necessary changes if any are needed. Other items to assessed are provider knowledge of where to find AD in the EMR and knowledge of how to bill an ACP session.

Clinic Processes. The office staff included in identifying office processes will be those who interact with every patient (receptionist, scheduling, check out) and the medical assistants and or nurses of the providers used for the QI project. They will be asked two questions: “Do you ask every patient if they have an AD/DPOAHC?” and “What do you do if a patient tells you he/she has an AD/DPOAHC or presents you with one?” This information can be recorded and analyzed for consistency between staff and obtained to evaluate if any changes need to be made in clinic flow. Other processes to assess are clinic appointment time lengths, room size (to accommodate family members should the patient desire them to be in the conversation), and resources the clinic provides for patient education (if there is any).

Timing Advance Care Planning

According to Lunney, Lynn, & Hogan (2002) there are four main categories of illness trajectories: sudden death, terminal illness, organ failure and frailty. Most patients with heart failure fall into the categories of organ failure or frailty. Patients in either of these categories will oscillate between times of wellness and times of decompensation, all the while trending downward toward death. The extremes of wellness and disease are more exaggerated for those in

the organ failure category. For patients and families, these extremes are emotionally, physically and psychologically exhausting; just as the patient seems to get better, there is another decompensation (Alonso et al., 2017; Fitzsimons et al., 2019). In terms of the organ failure and frailty trajectories, it is difficult for providers to pinpoint the “right time” to discuss ACP issues. The optimum time to discuss patient wishes/preferences is when he/she is stable; however, this does not always occur.

About 50% of patients with heart failure have a reduced ejection fraction (HFrEF) with the other half having a preserved ejection fraction (HFpEF) (Shah et al., 2017). Despite advances in treatment for those with HFrEF and difficulties in treatment for those with HFpEF, mortality rates remain equally high in both groups. It is often quoted that 50% of individuals will die within 5 years of diagnosis, however, Shah et al. (2017) found this number to be as high as 75% (Lewin & Schaefer, 2017). The one-year mortality for patients after their first hospitalization and for those experiencing NYHA class IV symptoms is 30% and 75% respectively (Chen-Scarabelli, Saravolatz, Hirsh, Agrawal, & Scarabelli, 2015). In this disease, most patients do not survive long enough to be categorized with end-stage heart failure (AHA stage D) (Whellan et al., 2014). Despite this, most conversations about ACP do not occur until all treatment measures have been attempted, at the end of the illness trajectory.

Triggering Patient Conversations. It is impossible to predict which patients will die suddenly and which patients will reach end stage heart failure. While ACP is a topic that should be discussed more frequently and at specified points in a patient’s trajectory, the reality is quite different (Bernacki & Block, 2014; Dunlay et al., 2015; Klindtworth et al., 2015). The AHA consensus statement of 2012 and Dunlay & Strand (2016) give suggestions for important triggers of when ACP conversations should take place. The triggers include

- 1) annual visits
- 2) repeated hospitalizations/ER visits
- 3) change in function/health status (loss of ADLs, falls, change in living situation)
- 4) disease progression (increase symptom burden/decreased QOL)
- 5) new comorbid conditions
- 6) serial increases in maintenance diuretic doses
- 7) ICD shocks (Allen et al., 2012)

In addition to the above suggestions, those with end stage heart failure (AHA stage D or NYHA stage IV), and any patient diagnosed with heart failure who does not have any ACP documentation should be a priority for an ACP conversation.

Providers should be aware of and educated regarding these triggers at the beginning of the QI project. It may be helpful to have the medical assistant or RN fill out a form similar to the template in Appendix G while rooming the patient. This will give the clinician real time information regarding patient AD status and need for ACP conversation, and may keep ACP in the front of the clinician's mind.

Heart Failure Prediction Tools. Some clinicians prefer to use a prediction tool to evaluate the need for an ACP conversation. There are several prediction tools available for clinicians, each having their advantages and pitfalls.

One of the most popular tools is the Seattle Heart Failure Model, which is a prognostic tool used to estimate a patient's 1, 2 and 3-year survival (Levy et al., 2006). This tool has been validated by multiple cohorts (Levy et al., 2006). It is available as a calculator free online through the University of Washington (University of Washington, 2017). While unable to predict the future, this model provides additional information for the clinician on the urgency of

scheduling an ACP conversation with a patient. The online calculator can be found at the following link: <https://depts.washington.edu/shfm/?width=1536&height=864>.

The Cardiovascular Medicine Heart Failure Index (CVM-HF) is another prognostic tool for clinicians, but this tool calculates odds mortality instead of survival (Senni et al., 2006). It has been validated in heart failure populations and can be quickly calculated using a pen and paper. The table can be found in Treece et al., 2018.

The “Surprise Question” is a simple, quick, albeit semi effective tool used to evaluate patients for those clinicians who cannot (or do not) want to calculate using a tool. It is “Would it surprise you if this patient were to die within the next year?” It is based on clinician gestalt and during systematic reviews has been found to be semi-effective at predicting patient mortality (Downar, Goldman, Pinto, Englesakis, & Adhikari, 2017; White, Kupeli, Vickerstaff & Stone, 2017). This question performs better in the cancer population and when used by clinicians instead of nurses. One study modified the question for the primary care setting to include patients who would die within the next two years (Lakin et al., 2017). It is generally agreed that this should not be the only tool used to evaluate patients but should be used in conjunction with others to evaluate patient mortality (Downar et al., 2017; White et al., 2017). This question is used as part of a heart failure palliative care consult at University of Kansas Health System (S. Sanders, personal communication, January 8, 2019).

The ePrognosis tool, also known as the Gange index, is a free online tool that combined the Charlson and Elixhauser measures to predict one-year mortality in community dwelling adults ≥ 65 (Gange, Glynn, Avorn, Levin, & Schneeweiss, 2011). The benefit of this tool is it considers other comorbidities and medical conditions in addition to heart failure to predict an individual’s mortality risk. This tool was validated in a cohort of 120,679 Medicare enrollees in

Pennsylvania (Gange et al., 2011). The tool can be found at the following link:

<https://eprognosis.ucsf.edu/gagne.php>.

Proper Documentation of Visit

In order to receive payment, there are certain aspects that must be included in ACP documentation. To summarize from the literature review, the ACP conversation must be face-to-face, can be performed by a physician, APRN, physician assistant or RN, billed during multiple encounters, and can be with the patient, family member(s), and/or surrogate (Moore & Hays, 2016; Sonenberg & Sepulveda-Pacsi, 2018).

Time Requirements. As 99497 and 99498 are time-based codes, the time spent conducting the ACP conversation must be included. The 99497 code is for the first 30 minutes of the conversation and 99498 for any additional 30 minutes. To fulfill the time requirements, the clinician must past the midpoint of the time requirement. Thus, to bill for a 99497, the conversation must have taken at least 16 minutes (Davies, 2017). To bill for a 99498 when attached to a 99497, the conversation must have taken a total of at least 46 minutes (30 minutes for the 99497 and 16 minutes for the 99498). If this is being added onto an Evaluation and Management (E&M) visit, this time must be in addition to the E&M time and not in lieu of it (Moore & Hays, 2016).

Example documentation of the following would fulfill the requirement for 99497: “I have spent more than 16 minutes in face to face discussion of patient condition, prognosis, treatment goals, and advance care planning with the patient and/or surrogate decision makers” (R. Studnicka, personal communication, January 11, 2019). Example documentation of the following would fulfill the requirement for 99498 when attached to a 99497: “I have spent a total of 46 minutes in face to face discussion of patient condition, prognosis, treatment goals, and advance

care planning with the patient and/or surrogate decision makers” (R. Studnicka, personal communication, January 11, 2019).

Note Requirements. Further documentation includes individuals who were present for the ACP conversation, details of the conversation with patient/family quotations included, the outcome of the conversation, possible documents completed during the conversation, and other documents available that further outline patient/surrogate wishes (MOLST/POLST/TPOPP). Details of the conversation should include general information, such as the patient’s values and preferences, fears and concerns, and specifics regarding life sustaining treatments, future hospitalizations, and hospice care (Dingfield & Kayser, 2017; R. Studnicka, personal communication, January 11, 2019). Patient illness, disease trajectory and poor prognosis should also be included (Dingfield & Kayser, 2017). An example template and an example note can be found in Appendices H & I.

Common Barriers to Advance Care Planning

Barriers to ACP are well documented in the literature and include lack of time, training, knowledge regarding available tools, staff, and clinician or patient discomfort with the subject (Dube et al., 2015; Waldrop & Meeker, 2012). While compensation for ACP conversations is now available, if not already in place at a clinic, there can be considerable overhead in order to train staff and restructure clinic flow. Barriers to ACP and resources for barrier removal will now be discussed.

Clinician Training. Lack of clinician training is one of the most oft cited reasons ACP is not completed (Alonso et al., 2017; Hupcey et al., 2016; Lum & Sudore, 2016; Meyers & Goodlin, 2016). Fortunately, there are many resources available for clinicians to obtain training in this subject. Some are free, while others require payment.

The Serious Illness Conversation Guide (SICG) (Appendix J) is a tool that can be used to guide ACP conversations. Ariadne Labs developed the SICG through a national panel of experts that included patients and had providers from fields such as oncology, palliative care, internal medicine, cardiology, pediatrics, and surgery (Bernacki et al., 2015). Following development, the SICG was presented to the Patient and Family Advisory Council and given to a marketing firm to perform focus groups with patients, families and providers (Bernacki et al., 2015). Each group gave feedback for terminology and format refinement. Next a pilot group of 26 providers used it in practice and gave 3 cycles of feedback until the final guide was produced (Bernacki et al., 2015). The SICG can be downloaded for free when individuals sign up for Ariadne Lab's free membership. After signing up, clinicians can join different community groups. This gives access to a greater number of resources that go in depth regarding the SICG, its development and usage, tips for organizational implementation, a community forum to discuss questions with other clinicians, and videos and webinars.

There is a one-hour webinar available on YouTube that gives an overview of how to use the SICG when talking with patients that is available here:

<https://www.youtube.com/watch?v=vMHe0q2gpCI&t=7s>. There are also two shorter videos that demonstrate the use of the SICG which can be found here:

<https://www.youtube.com/watch?v=xL11HICcNYM> and
https://www.youtube.com/watch?v=fhwa9f5O_U4.

Vital Talk is a nonprofit organization developed to disseminate their research on communication to clinicians (Vital Talk, 2018). They have developed online and in-person training courses and tools to better assist clinicians in communicating with patients about delicate topics. Their tools range from basic to in-depth, with the basic consisting of free videos

and worksheets for clinicians to view on their website and more in-depth courses having a cost attached. The free videos include Vital Talk's core techniques and tools. The Disclose Serious News section is 5 videos that total in 4 minutes and 30 seconds. The Address Goals of Care section is 10 videos that total in about 16 minutes. The Conducting a Family Conference section is two videos totaling about 7 minutes. Other free sections include Establish Rapport, Offer Prognostic Information, Track and Respond to Emotion, Defuse Conflicts, Stay Strong, Bear Witness to the End, and Cultivating your skills (Vital Talk, 2018). Most sections have free guides that can be printed for clinician use during ACP conversations. The guides are also freely available on the Vital Talk apps (on Apple and Android). Cost for the courses range from a \$110 online course, a \$500 workshop, and a \$2,500 conference that allows the clinician to become a trainer (Vital Talk, 2018).

The Center to Advance Palliative Care (CAPC) is another clinician resource. Established in 1999, the CAPC was created to improve patient care and assist health care organizations in developing palliative care programs throughout the U.S. (Center to Advance Palliative Care [CAPC], 2019).

They provide training through courses, webinars, CMEs and CEUs, and discussion forums. For access to their products there is one annual membership fee and then all individuals of the organization have access. The annual fee for an outpatient clinic is \$3,500 (CAPC, 2019).

Patient Comfort. Part of ACP is assessing patient readiness. Some patients need more time than others to process their thoughts and prepare for an ACP conversation. Using the list of patients who do not have ADs, which was compiled during the assessment, prioritize them according to the above suggestions. During the appointment reminder message let the patient know that there is a QI project going on, all patients are being assessed for an AD, and he/she did

not have one (or it needs to be updated). A discussion regarding ACP will be conducted at his/her next appointment and the patient can bring family members to the appointment for the discussion if he/she chooses. Ariadne Labs, who created the SICG, has also created a pre-visit letter that can be mailed or emailed to selected patients to assist in patient readiness (Appendix K). This is available at no cost for those who have signed up for their free membership.

If the office has chosen a tool to use that is asynchronous (see patient resources below) to the appointment, this would also be the time to tell the patient to review the tool prior to coming to the appointment. This way, any questions can be answered by the clinician.

If the patient is hospitalized and the clinic is associated with the hospital, many clinics are notified that the patient is in the hospital and is scheduled for a follow up clinic appointment within 2-4 weeks. The time to introduce this information would be at discharge from the hospital so the patient could review the information before the following appointment. One of the team members can meet with hospital case management to ensure the information is passed along to the patient.

Patient Resources. There are two types of resources for patients: synchronous (viewed/read in office) and asynchronous (view at home/at the patient's leisure). Each have their advantages and disadvantages, but both can be useful in increasing patient understanding and preparedness for participating in an ACP conversation. Some end with the production of an AD.

Five Wishes is a program created by the nonprofit organization Aging with Dignity (Aging with Dignity, 2018). For \$5.00 anyone can use their program to create an AD. It is user friendly, available online or as a hardcopy, and is easy for non-medical personnel to understand (Aging with Dignity, 2018). There are also resources for providers, including an instructional video, conversation guide, and the ability to buy the Five Wishes document in bulk. Kansas is

one of ten states that requires patients to fill out an additional form after completing their Five Wishes document to make the information legally-binding. Their information can be found at <https://fivewishes.org/Home>

Making Your Wishes Known (MYWK) is an online tool that assists adults in completing an AD. Clinicians can also use MYWK to facilitate ACP conversations with patients. Making your wishes known has been found to increase ACP knowledge in patients, and patients have reported being highly satisfied with how the tool presents information and the accuracy of the final AD (Myers et al., 2018; Van Scoy et al., 2016). Their information can be found at <https://www.makingyourwishesknown.com/default.aspx>.

The Conversation Project is a public engagement initiative began by IHI with the goal of having all people express their end-of-life wishes so they can be respected (IHI, 2018b). They provide conversation starter kits for patients and family members to assist them in having an ACP discussion amongst themselves and with their clinicians. They also provide information about how to choose or be a healthcare proxy (IHI, 2018b). Starter kits are available for free if downloaded electronically and can be purchased as a hard copy for \$3.05 each with a minimum of 25. An AD is not created at the end of the starter kit, however much of the necessary information needed for an AD is discussed in the starter kit. Their information can be found at <https://theconversationproject.org/>.

PREPARE for your care has a free online tool and easy to read AD which has been created, tested and validated by researchers (Lum et al., 2018; Sudore et al., 2007; Sudore et al., 2017). The PREPARE tool is free and has videos and questions to assist patients in understanding ACP, how to make decisions, and incorporating their values into those decisions (Lum et al., 2018; PREPARE for your care, 2018; Sudore et al., 2017). There is also an easy-to-

read AD that has been validated and is free for use after the video tool. The video tool and documents have been found to increase ACP conversations among family members and between patients and their clinicians and increase ACP documentation among clinicians (Lum et al., 2018; Sudore et al., 2017). Individuals have rated the easy to read AD as easy to use, were highly satisfied, and would recommend it to others (Sudore et al., 2017). Their website is <https://prepareforyourcare.org/welcome>.

A dilemma in EOL care for some in the heart failure population is surgically placing an ICD, cardiac resynchronization therapy with defibrillator (CRT-D) or left ventricular assist device (LVAD) in a patient. While this sustains life, there is a great deal of confusion regarding when and how to shut off these devices (Whellan et al., 2014). While not an ACP tool, the Colorado Program for Patient Centered Decisions developed four decision aids pertaining to the ICD (initial and replacement of), CRT-D and LVAD. These decision aids can assist patients and clinicians in performing ACP conversations and making decisions with those that have these devices (McIlvennan, 2017). There is currently a RCT in six hospitals across the U.S. to evaluate the effectiveness of these decision aids (McIlvennan, 2017). They are available free of charge at <https://patientdecisionaid.org/>.

The Quality Improvement Project

General Quality Improvement Project Information

A quality improvement project (QI) is a continuous process of planning, testing and spreading change in an already established organization to better patient experience, improve processes, and increase the quality of care delivered in a measurable way (Agency for Healthcare Research and Quality [AHRQ], 2017b). This can be a daunting task, no matter the organization size. Research has indicated that the largest companies that function most effectively and have the most success in QI focus on the smaller, functional units that carry out the main activities of

the company. These smaller functional units are referred to as “microsystems” (AHRQ, 2017b). Examples of microsystems can include a patient’s care team (provider, nurses, medical technicians), staff who work with a specific patient population, or work areas linked together through processes (AHRQ, 2017b). Placing the QI project in the appropriate microsystem makes the task less intimidating and assists in identifying stakeholders and team members and determining the scale of the project (AHRQ, 2017b). Once the microsystem is identified, the beginning steps for a QI project can begin (Silver et al., 2016).

For the purposes of this project, the setting is an outpatient heart failure clinic. The microsystem is the individuals a heart failure patient would see and speak with during an outpatient visit. This includes the front office staff, medical assistants (MA), registered nurses (RN), and the clinician. Many clinicians have their own specific MAs or RNs assigned to them, and this could further concentrate the microsystem, focusing on a small number of clinicians and their respective MA and/or RN.

Determining stakeholders. A stakeholder is any person, group or organization who may be involved in the project or is interested in the outcome (Zaccagnini & White, 2017). These individuals can be on micro or macro levels and can affect, or be affected by, the project (Moran, Burson & Conrad, 2017). Identifying all stakeholders will assist in finding key individuals for the QI project team as well as detect those who could benefit/block the project (Moran et al., 2017). A useful way to identify stakeholders is to brainstorm a list and categorize them into groups. A concept map is useful to visualize the stakeholders and the relationships between them (Silver et al., 2016). An example concept map can be found in Appendix L.

Once identified, stakeholders should be analyzed and categorized for interest in and power over the project (Silver et al., 2016). A 2x2 grid can be developed, with the y-axis used for

stakeholder power over the project and the x-axis used for stakeholder interest in the project, leading to four categories of individuals (Silver et al., 2016). An example grid can be found in Appendix M.

Forming the Team. Once the stakeholders are analyzed, the roles of the QI team need to be filled. The following are general recommendations of team positions, but other positions may be needed depending on the organization and project (Department of Health and Human Services Health Resources and Services Administration [HRSA], 2011; Silver et al., 2016):

- Team Lead: Person responsible for the day to day and overall management of the project.
- Clinical Leader(s): Provider(s) who is/are responsible for championing the QI initiative in the targeted patient population. These persons understand how changes will affect different roles in clinic and are able to collaborate and influence those affected by QI changes.
- Technical Expert(s): Individual(s) responsible for data entry and management and any technical assistance needed for the project (Example is electronic medical record (EMR) expert if changes need to be made in EMR).
- Executive Sponsor: Individual in leadership who can support the QI project among administration, approve different aspects of project, approve supplies, and remove barriers, etc.

Physicians are an important part of the QI team because of their influence on healthcare outcomes, and are interested in quality, delivery and efficiency of care; however, there are many barriers to physician involvement including lack of time, financial incentives, and quality

improvement skills (Silver et al., 2016). If on the QI team, but not the team lead, physicians must try not to control the project (Silver et al., 2016).

Patients or family members can also play an important role on the QI team. Advantages to involving users of the healthcare system include challenging assumptions of the current system, energizing staff and focusing team members (Silver et al., 2016). Their main disadvantage is when patient/family involvement is mandated, making his/her involvement perfunctory to the team and insulting to the individual (Silver et al., 2016).

Particularly with the subject of ACP, it is especially important to find both executive and day-to-day leadership for the QI team in order to hold others accountable and track changes (Dixon & Knapp, 2018; Reidy et al., 2017). Dixon & Knapp (2018) conducted a qualitative interview with 12 institutions in 4 different countries and noted that ACP awareness and urgency declined quickly and significantly when senior level champions left their positions.

Selecting the QI Framework. An improvement framework provides structure and can help naturally guide the QI project (Silver et al., 2016). Several frameworks exist, and the most popular ones have overlap between them; therefore, choosing one should not be onerous (Silver et al., 2016). It is recommended that preference should be given to the framework team members have the most familiarity with.

Six Sigma. Developed by Motorola in the 1980s, Six Sigma uses quantitative tools to understand and control processes with the goal of improving quality and reducing variability (Moran et al., 2017; Silver et al., 2016). Quality improvement projects using Six Sigma use five phases, also known as the DMAIC process, to guide improvement (Moran et al., 2017). Different tools can be used in each phase to assist the project.

1. Define- What is the improvement opportunity and how will success be measured

2. Measure- Determine current processes and gather needed data for a baseline
3. Analyze- Use data to find cause of current problems and/or areas for improvement
4. Improve- Make changes to current process based on findings from analysis; test the solutions
5. Control- Ensure that changes can be sustained

Lean. Toyota is credited with developing this framework, which has two themes: respect for people and continuous improvement by eliminating waste (Silver et al., 2016). This framework does not use statistical analysis to reduce variation, and training in this method assists the user in skillful implementation. This framework applies best to situations where waste can be eliminated and speed, efficiency and flow are priorities that are directly observable (Silver et al., 2016).

TeamSTEPPS. Developed by the U.S. Department of Defense and the Agency for Healthcare Research and Quality, TeamSTEPPS intent is to improve healthcare quality, patient safety, and team collaboration through free resource training (Moore, 2017). TeamSTEPPS has demonstrated success in a variety of healthcare settings (Moore, 2017). There are three phases to the TeamSTEPPS system (AHRQ, 2017a):

1. Assess the Need
2. Planning, Training and Implementation
3. Sustainment

TeamSTEPPS is a useful framework because it is a comprehensive set of evidence-based curriculum designed to improve communication and improve quality in different settings (AHRQ, 2017a). The curriculum for this project would be the Office Based Care version. The curriculum is available as a classroom course, online course, or hybrid course. While all

resources are provided at no cost, the training for TeamSTEPPS is lengthy. The instructor guides are also provided, but this requires additional training as well.

Model for Improvement. Developed in the 1990s and popularized by the Institute for Healthcare Improvement, this model uses an algorithm focusing on the learned experience and purposeful action (Silver et al., 2016). Quality improvement is achieved by answering three questions (Institute for Healthcare Improvement [IHI], 2018a):

1. What are we trying to accomplish?
2. How will we know a change is an improvement?
3. What changes can we make that will result in improvement?

This model is recommended because it is simple and efficient to use, and those with limited QI knowledge can utilize this model easily. It uses frontline staff to predict what changes will lead to an improvement. The main tool is the Plan-Do-Study-Act (PDSA) cycle, which is used to continually evaluate the changes made based on the how the original three questions were answered (IHI, 2018a; Silver et al., 2016). Using the PDSA cycle, individuals should not expect to find the perfect solution immediately. It allows users to test changes on a smaller scale, and if found useful, to expand those changes further (Silver et al., 2016). This model does not assist the users in identifying the cause of a quality of care problem and should be used with problems that have clear causes (Silver et al., 2016).

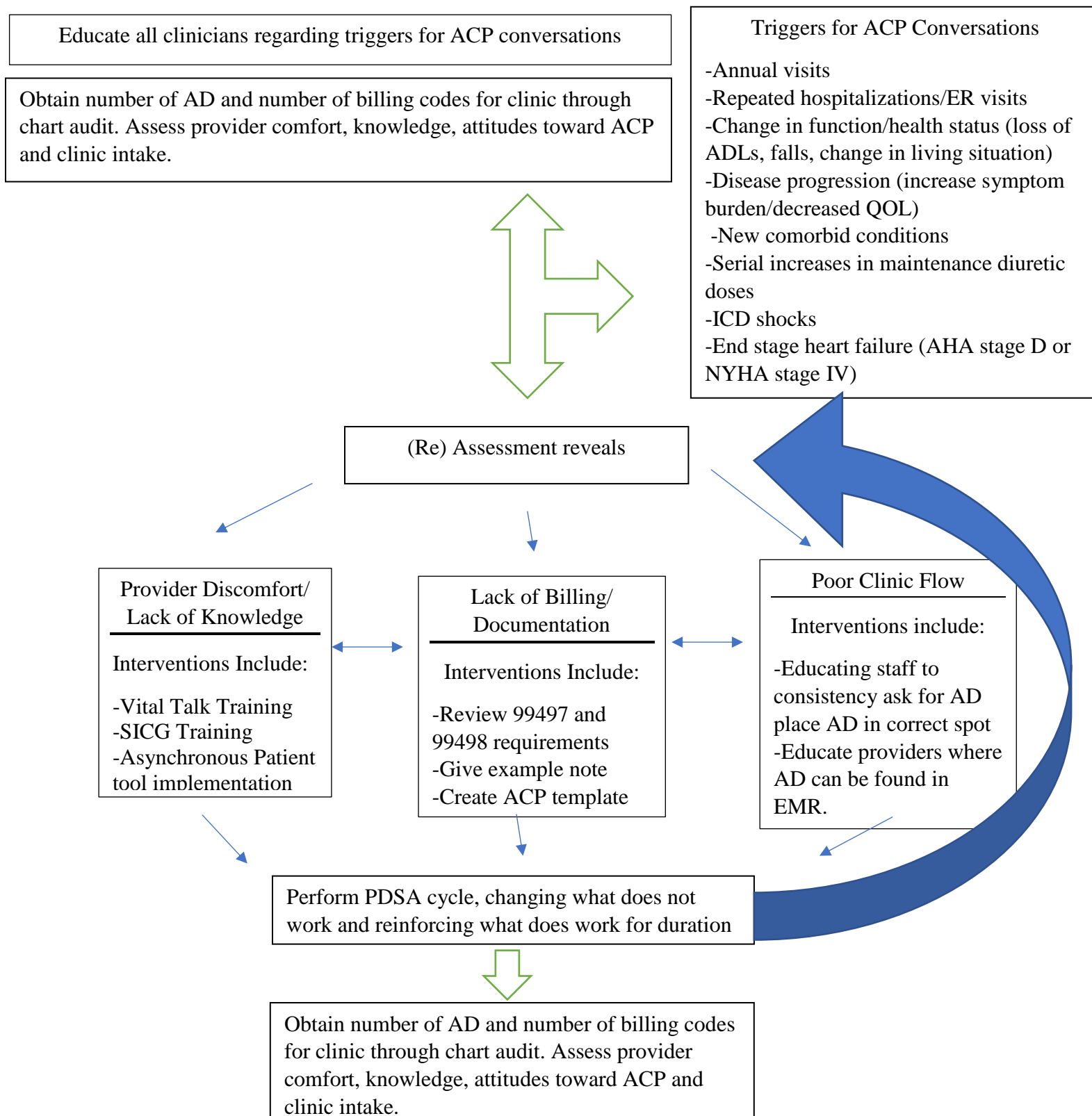
Obtaining Quality Improvement Approval. Some institutions require submission to IRB, while others to certain committees before beginning the project. These regulatory bodies will ask for information regarding the QI project and will determine if the institution would like it to go forward, be revised, or not completed at all. Having an executive sponsor as a team member will assist in this area.

Assessing Implementation with PDSA Cycle

After implementing a QI initiative, it is important to evaluate what is and is not working. This PDSA cycle gives flexibility and fluidity throughout the quality improvement process and will assist in keeping the team on task to meet the end goals by answering the initial three questions. Team members should meet once a month to go through the PDSA cycle and make necessary changes in the project.

Appendix B

Protocol Algorithm



Appendix C

Matrix of Advance Care Planning Tools

Author, Year, tool used	Study Design	Sample characteristics and setting	Major Variables	Outcome Measures	Data Analysis	Findings	Level of Evidence
Lum et al., 2018 -Tools: Easy to read AD and PREPARE website	-Single blind, parallel-group, RCT*	-Veterans >60 with ≥2 chronic conditions, ≥2 visits with PCP in past year, and ≥2 ER, hospital, or outpatient visits in past year. -N=414 -General medicine outpatient clinics at San Francisco VA	-Intervention and control groups received ACP engagement survey.	-Primary outcomes: Assess behavior change processes and actions, including discussions with family members, friends, and surrogates, and documentation	-Baseline characteristics between groups compared X ² . -Mixed effects linear model compared subscale scores of surveys. -Baseline and 6 months follow up scores compared.	-Both intervention and control groups increased almost all subscales of survey. -95% of study participants reported increased action measures related to ACP discussion and documentation -Only scale not to show an increase was in asking clinicians questions.	-LOE: II

*RCT=Randomized Controlled Trial

Author, Year, tool used	Study Design	Sample characteristics and setting	Major Variables	Outcome Measures	Data Analysis	Findings	Level of Evidence
-El- Jawahri et al., 2016 -Tool: ACPDecision.org videos	-RCT*	-≥64-year-old, English speaking patients with established diagnosis of advanced heart failure. -N=246 -Multisite inpatient teaching hospitals around U.S.	-Intervention group: Received description of 3 GOC ⁱ read by research assistant, viewed 6-minute GOC video, received an ACP checklist. -Control group: Received description of 3 GOC read by research assistant	-Primary outcome: Patients in intervention group would prefer care focused on QOL ^j and comfort compared to control group. -Secondary outcomes: Intervention group would desire CPR ^o /ventilator or less, be more knowledgeable about ACP, and have more ACP conversations with clinicians.	-Compared GOC and CPR/intubation desires between groups using X ² . -Compared mean knowledge scores of groups using 2 sample t test. Used κ statistics for agreement in each study arm.	-Intervention arm: 22% preferred life prolonging care, 51% comfort care, 25% limited medical care, and 2% were uncertain. Control Arm: 41% preferred life prolonging care, 22% limited medical care, 30% comfort care and 7% uncertain (P<0.001). -Intervention arm 68%/78% would forgo CPR/Intubation vs 35% /48% in control arm (P<0.001 and P<0.001). -With baseline scores similar, intervention arm participants had higher mean knowledge scores regarding ACP options (4.1±1.4 vs. 3.0±1.5; P<0.001).	-LOE: II

*RCT= Randomized Controlled Trial; GOCⁱ= Goals of Care; QOL^j = Quality of Life; CPR^o =Cardiopulmonary Resuscitation;

Appendix D

Modified AGREE II Tool

DOMAIN 1. SCOPE AND PURPOSE

1. The overall objective(s) of the protocol is (are) specifically described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

2. The health question(s) covered by the protocol is (are) specifically described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

3. The population (patients, public, etc.) to whom the protocol is meant to apply is specifically described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

DOMAIN 2. STAKEHOLDER INVOLVEMENT

5. The views and preferences of the target population (patients, public, etc.) have been sought.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

6. The target users of the protocol are clearly defined

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

DOMAIN 3. RIGOUR OF DEVELOPMENT

7. Systematic methods were used to search for evidence.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

8. The criteria for selecting the evidence are clearly described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

9. The strengths and limitations of the body of evidence are clearly described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

DOMAIN 4. CLARITY OF PRESENTATION

15. The recommendations are specific and unambiguous.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

16. The different options for management of the condition or health issue are clearly presented.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

DOMAIN 5. APPLICABILITY

18. The protocol describes facilitators and barriers to its application.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

19. The protocol provides advice and/or tools on how the recommendations can be put into practice.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

20. The potential resource implications of applying the recommendations have been considered.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree
------------------------	---	---	---	---	---	---------------------

(AGREE Next Steps Consortium, 2017)

Appendix E
Demographic Information

- 1) Title (circle one): Physician Physician's Assistant Nurse Practitioner
- 2) Years of experience as a cardiology provider: _____
- 3) Age: _____
- 4) Gender: _____
- 5) Location of Clinic (rural vs. metropolitan): _____

Protocol Review Questions

- 1) After reviewing the protocol and using the modified AGREE II tool, how feasible do you think it is to implement this protocol in your clinic?

- 2) How do you think this protocol could be made stronger/ more complete?

- 3) What are the barriers you see to implementing a protocol like this?

- 4) Do you think this protocol, or something like it, would be useful to you or your clinic?

Appendix F

Advanced Care Planning Provider Questions

Advance care planning (ACP) is the process of discussing a patient's medical wishes and goals in the event they cannot make decisions for themselves. This discussion goes beyond, "If you were unresponsive and needed CPR, defibrillation, a breathing tube, or other life-sustaining measures, would you want it?" ACP is a discussion about goals of care, which ensures that patients understand their illness and disease trajectory; furthermore, it explains and offers interventions that best align patients' goals. This is a process and not a one-time discussion and should be re-evaluated periodically. Knowing this, please answer the following questions.

1) What is your way of knowing when an ACP conversation needs to take place?

2) How comfortable are you facilitating an ACP discussion? (please mark where you fall)

Not Comfortable-----Somewhat comfortable-----Comfortable-----Very Comfortable

3) Do you have a format you follow for ACP discussions? Yes No

If so, what format do you use and where did you obtain it from?

4) Do you feel that ACP discussions are your responsibility? Yes No

5) Do you know where you can get resources for patients or yourself if needed?

Yes No

6) Where can you find a patient's AD in the chart?

7) Do you know how to bill for an ACP conversation?

Appendix G

Clinic Flow Sheet to Identify Patients for ACP

Does the patient have an AD? Yes No

If no, has the patient recently experienced any of the following? (Circle all that apply)

Recent hospitalizations/ER visits due to heart failure

Change in function/health status (loss of ADLs, falls, change in living situation)

Signs of disease progression (increase symptom burden/decreased QOL)

New comorbid conditions

Increase in maintenance diuretic doses

ICD shock

Appendix H

Example of ACP Documentation Template

Advance Care Planning/Goals of Care Conversation

Persons present for conversation: (Put names and relationship to patient)

Medical Condition/ Comorbidities: (Could be useful if it self populates)

Details of conversation (include direct quotes from patient or surrogate): Patient's values, concerns, fears, preferences, and specifics of life preserving interventions, future hospitalizations, and hospice.

Outcome of Conversation: (Desire for future hospitalizations, code status if hospitalized)

Documents completed as a result of conversation: (AD, Living Will, DPOAHC, TPOPP, POLST/MOLST)

Other documents present that outline patient/surrogate wishes:

Time: "I have spent a total of ____ minutes in face to face discussion of patient condition, prognosis, treatment goals, and advance care planning with the patient and/or surrogate decision makers."

Appendix I

Example of ACP Documentation

Advance Care Planning/Goals of Care Conversation

Persons present for conversation: John (patient), Samantha (Wife), and children Ryan and Kelsey.

Medical Conditions/Comorbidities: Coronary Heart Disease, Aortic stenosis with TAVR, GERD.

Details of conversation (include direct quotes from patient or surrogate): John and his family watched the PREPARE for your care online tool. John has decided to make his son, Ryan, his DPOAHC.

John stated “I would prefer a life that I could actually live, instead of living in the hospital, or on a machine. But if there is something that could be done to fix whatever is wrong with me, I would be open to that. Like when there was something wrong with my heart valve. They replaced it and my symptoms got a lot better.”

John wants a full code status in the hospital.

John stated, “If it is my time to die, then I am alright with that. I need the you and the other doctors to tell me what is realistic and what is not.”

Outcome of Conversation: Full code status if hospitalized.

Documents completed as a result of conversation: DPOAHC- Son Ryan

Other documents present that outline patient/surrogate wishes: None

Time: “I have spent a total of ____ minutes in face to face discussion of patient condition, prognosis, treatment goals, and advance care planning with the patient and/or surrogate decision makers.”

Appendix J

Serious Illness Conversation Guide

CONVERSATION FLOW

1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

2. Assess understanding and preferences

3. Share prognosis

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

4. Explore key topics

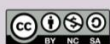
- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

6. Document your conversation

7. Communicate with key clinicians



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Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

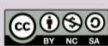
SET UP “I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**”

ASSESS “What is **your understanding** now of where you are with your illness?”
 “How much **information** about what is likely to be ahead with your illness would you like from me?”

SHARE “I want to share with you **my understanding** of where things are with your illness...”
Uncertain: “It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I’m **worried** that you could get sick quickly, and I think it is important to prepare for that possibility.”
 OR
Time: “I **wish** we were not in this situation, but I am **worried** that time may be as short as ____ (*express as a range, e.g. days to weeks, weeks to months, months to a year*).”
 OR
Function: “I **hope** that this is not the case, but I’m **worried** that this may be as strong as you will feel, and things are likely to get more difficult.”

EXPLORE “What are your most important **goals** if your health situation worsens?”
 “What are your biggest **fears and worries** about the future with your health?”
 “What gives you **strength** as you think about the future with your illness?”
 “What **abilities** are so critical to your life that you can’t imagine living without them?”
 “If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?”
 “How much does your **family** know about your priorities and wishes?”

CLOSE “I’ve heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we _____. This will help us make sure that your treatment plans reflect what’s important to you.”
 “How does this plan seem to you?”
 “I will do everything I can to help you through this.”



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(Bernacki & Block, 2014)

Appendix K

Talking with your clinician about the future

At your scheduled visit, your clinician would like to talk with you about your illness, your goals and wishes, and planning for the future. This is an important part of the care we provide for all of our patients.

Our team likes to start talking about this when patients are doing okay. Your illness is serious but stable, so now is a good time to talk about what is ahead, and to do some planning for the future. Patients who think through what is important to them and what their wishes are often feel less anxious, more at peace, and more in control of their situation.

Before your next meeting

Please prepare for your conversation by thinking about these things:

- ‘ What would you like to know about your illness and what is likely to be ahead?
- ‘ What kind of information would help you make decisions about your future?
- ‘ What is most important for you to have a good quality of life?
- ‘ What are you afraid of about your illness?
- ‘ What kinds of medical care do you not want?
- ‘ What do you think it would be like to share these thoughts with your family?
- ‘ If you haven’t already identified a health care proxy, who would be able to fill that role?

Please bring to your visit:

- ‘ If you have a health care proxy form that is not on file at the hospital, *please bring a copy*.
- ‘ If you have a living will or advance directive, *please bring a copy*.

If you don’t have these documents or have questions about them, talk to your clinician.

Why is this important?

Thinking about and sharing your wishes will give you more control over the care you get. It will also help prepare your loved ones to make decisions for you if you can’t make them at some point in the future. Knowing what you want will ease the burden on your family of making hard decisions for you if you can’t speak for yourself.

Talking about the future won’t change your ongoing care

Talking about the future won’t change the plans we have made so far about your treatment, unless, of course, you want to. We will keep providing the best possible care to control your disease.

You may find it helpful to bring other people to your next appointment

You can choose to bring the person who is your health care proxy or other family members to your next visit so they can be a part of the conversation. You can also bring your nurse practitioner, social worker, or chaplain if you like. Please let your clinician’s office know if you would like to bring others to the appointment.

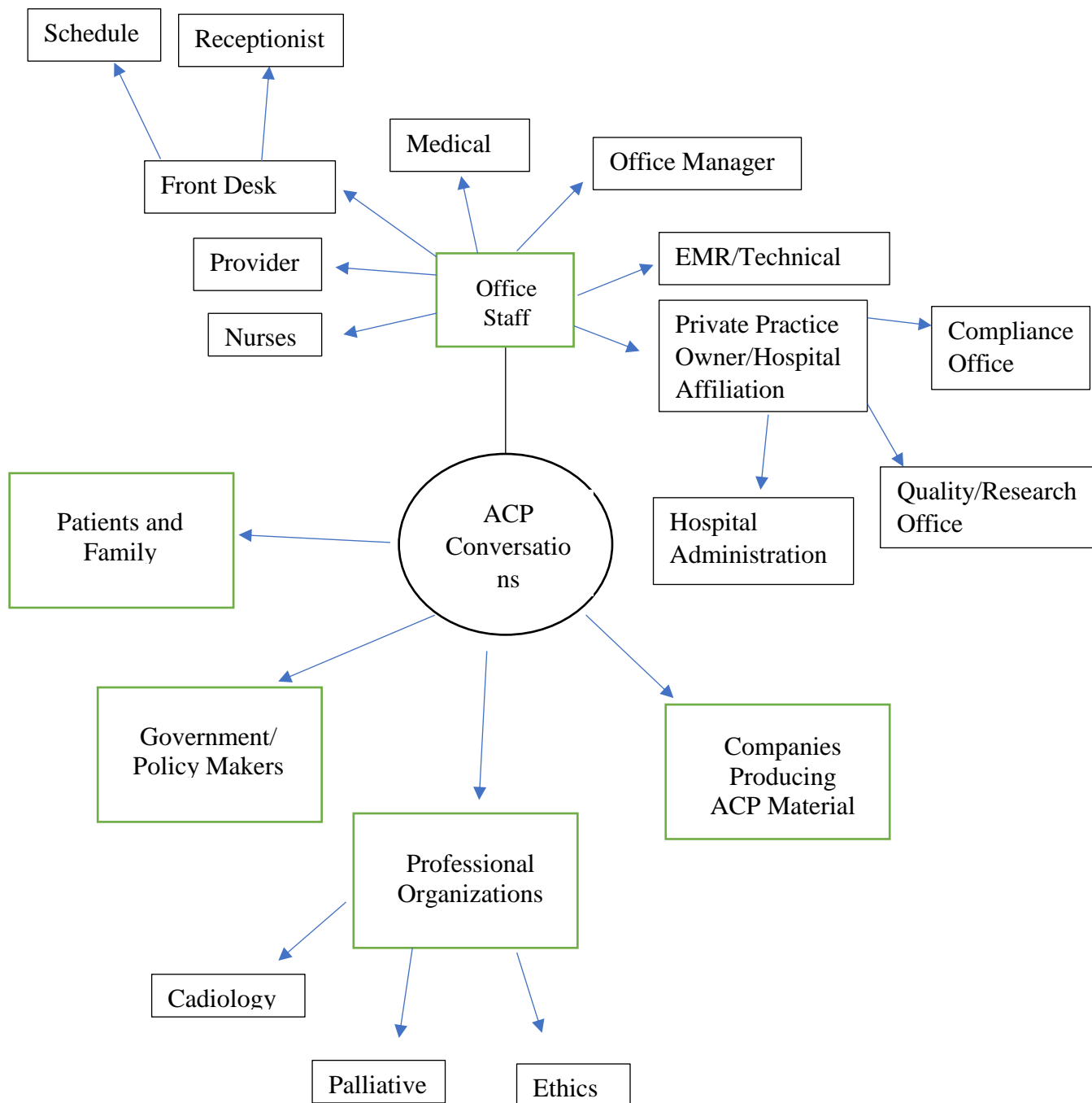
We understand that your wishes may change over time

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions.



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Appendix L
Stakeholder Concept Map



Appendix M
Power Versus Interest Grid

Level of Interest	High	<u>Subjects</u>	<u>Players</u>
		-Patients -Family Members	-Providers -Office Manager -Private Practice Owner/Hospital Affiliation
Level of Interest	Low	<u>Crowd</u>	<u>Context Setters</u>
		-Scheduler -Receptionist -Medical Assistants -Nurses -EMR/Technical staff	-Companies producing ACP material -Professional organizations -Government/Policy Makers
		Low	High
		Level of Power	

Silver et al., 2016

Subjects- Individuals with high interest and low power

Players- Individuals with high interest and high power

Crowd- Individuals with low interest and low power

Context Setters- Individuals with low interest and high power